DOCUMENT RESUME

ED 263 704 EC 180 971

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TITLE Euthanasia, Selective Abortion and Educability: A Survey of the Literature and the TASH Membership.
PUB DATE [82]
NOTE 29p.
PUB TYPE Reports - Research/Technical (143)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Abortions; Ethics; Infants; Mass Media; Publicity; *Severe Disabilities; *Severe Mental Retardation; Values
IDENTIFIERS *Euthanasia

ABSTRACT

The study explored what sources were responsible for exposing professionals to issues of euthanasia of handicapped infants, selective abortion of severely handicapped fetuses and the educability of profoundly retarded persons, and what sources professionals thought were most appropriate for the dissemination of information. The study consisted of two parts: (1) a review of four journals to examine coverage of the issues, and (2) a survey administered to The Association for the Severely Handicapped (TASH) membership to examine members' perceptions on the coverage of the issues and TASH's role in the issues. The review of the journals resulted in a total of 23 issue articles in 10 years. The survey suggested that the mass media was providing most of the information on euthanasia and selective abortion, while professional journals provide the most coverage of the educability issue. Respondents (N=90) saw a general need for more coverage on all of the issues. Data also suggest that selective abortion is the least agreed upon issue among respondents; there was a fairly equal split between those who thought that TASH should take a strong position on the issue and those who thought that TASH should avoid taking a position. References, tables, and the survey instrument are appended. (Author/CL)

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ED263704

EUTHANASIA, SELECTIVE ABORTION AND EDUCABILITY: A SURVEY OF THE LITERATURE AND THE TASH MEMBERSHIP

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Abstract

The issues of euthanasia of handicapped infants, selective abortion of severely handicapped fetuses and the educability of profoundly retarded persons present complex questions to professionals. The present study explored what sources were responsible for exposing professionals to these issues and what sources professionals thought were most appropriate for the dissemination of information. The study consisted of two parts: 1) a review of four journals to examine coverage of the issues, and 2) a survey administered to the TASH membership to examine members' perceptions on the coverage of the issues and TASH's role in the issues. The review of the journals resulted in a total of 23 issue articles in 10 years. The Survey suggested that the Mass Media was providing most of the information on euthanasia and selective abortion, while Professional Journals provide the most coverage of the educability issue. Respondents saw a general need for more coverage on all of the issues. Data also suggest that selective abortion is the least agreed upon issue among respondents; there was a fairly equal split between those who thought that TASH should take a strong position on the issue and those who thought that TASH should avoid taking a position.

EUTHANASIA, SELECTIVE ABORTION AND EDUCABILITY: A SURVEY OF THE LITERATURE AND THE TASH MEMBERSHIP[1,2]

There has been a growing recognition of many complex social and moral issues concerning the lives and education of severely and profoundly handicapped persons. Specifically, the issues of euthanasia of handicapped infants (e.g., Affleck, 1980; Cohen, 1981; Hardman & Drew, 1980; Powell, 1982; Stevens & Conn, 1976; Wolfensberger, 1980), selective abortion of severely handicapped fetuses (Davis, 1981; Hardman & Drew, 1978; Smith, 1981; Wolfensberger, 1980), and the educability of profoundly retarded persons, (Levy, Webster & Schenck, 1979; Noonan, Brown, Mulligan & Rettig, 1982) have been a growing concern to many professionals. These issues, perhaps a product of advances in medical and educational technology, present complex questions to professionals. Two of these issues, selective abortion and euthanasia, are concerned with a "life/death" question; that is, a decision is made that will either support or deny life, or development, of a severely handicapped individual. The educability issue, although not necessarily a "life/death" question, is concerned with the potential quality of life and fundamental rights of a severely handicapped person.

Some individuals are fairly resolved about any one or all of the issues. Others, however, find themselves unresolved after juggling with variables such as professional vs. personal feelings,

legal and civil rights, women's rights, and religious and moral feelings. Perhaps the lack of resolution is because some feel compelled to find a single position that fits all of the issues and all of their various roles in life, and at the same time is representative of some generalized "good" or "right" way to think. Other professionals, however, remain either unaware of the issues or perhaps unconcerned.

The present study was an attempt to explore what sources were responsible for exposing professionals to these issues. Further it examined what sources professionals thought were most appropriate for the dissemination of information. The study consisted of two parts: 1) a review of four journals to examine the coverage of the three issues from 1973-1982, and 2) a survey administered to the TASH membership to examine members' perceptions on the coverage of the issues and TASH's role in the issues.

Journal Review

The purpose of the Journal Review was to examine the journal as a source of availability of information on the three issues. A review was done on four publications thought to be read by many professionals in the area of severely handicapped. The four journals were: Journal of The Association for the Severely Handicapped (JASH), Education and Training of the Mentally Retarded (ETMR), Mental Retardation (MR), and American Journal of Mental Deficiency (AJMD). These journals represent three major professional organizations

that address research, education and services for handicapped individuals: The Association for the Severely Handicapped, Council on Exceptional Children, and American Association on Mental Deficiency. Each journal was reviewed for any articles or brief reports, from 1973-1982, that related to any of the issues. In order to be included in the count, the issue had to be a major focus of the article.

Results and Discussion. A total of 23 articles were found in the four journals. Table 1 lists the bibliographic information on each article. Table 2 summarizes the number of articles, by issue, found in each of the journals. There is a difference of three in the total number of issue articles indicated on Table 2 and the total of 23 stated above. This difference is due to the overlap of three articles; that is, three articles addressed both the euthanasia and the selective abortion issues.

Insert Table 1 about here

Table 2 indicates that MR is providing most of the coverage on the three issues, for a total of 15 articles. (There are actually 13 articles, however, two of the articles cover both selective abortion and euthanasia, and are therefore counted twice.) JASH and AJMD both have published a total of four articles, and ETMR has published three. (Again, one article covered in ETMR addressed both issues and is counted twice.) When considering these findings,

it should be noted that JASH was not established until 1976. However, JASH did not address any of the issues until 1981. Table 2 also indicates that euthanasia is the most covered issue, followed closely by selective abortion and the least amount of coverage was given to the educability issue.

Insert Table 2 about here

Survey

The purpose of the survey was to examine members' perceptions on certain aspects of the selective abortion, euthanasia and educability issues. The survey (see Figure 1) addressed three areas related to the coverage of these issues in various sources: Professional Journals, Conferences, School, Others in the field, and the Mass Media. "Degree of Exposure" surveyed what sources were providing the members with information on each of the issues. Members were asked to rank order, 0-5, the degree to which each source exposed them to each of the issues.

Members were also asked to respond to the "Adequacy of Coverage." This section required the respondent to indicate if he/she thought that each source should cover the issues "more," "less," or was "adequate" in its present coverage of the issue.

The third section of the Survey questioned members' feelings on the role that TASH should play in regard to each of the issues. That is, should TASH take a strong position or avoid a position on

each of the issues and/or should TASH present a forum for discussion for each issue.

Insert Figure 1 about here

Results and Discussion

The TASH membership Survey was distributed in the TASH Newsletter (Vol. 8 #9) to all 4731 members of TASH. A total of 90 surveys were returned for a return rate of approximately 2%. The author acknowledges the limitations of such a small return rate and cautions the reader against assuming that these data are necessarily representative of the TASH membership. The results, however, may still shed some light on the questions raised, and at least present a pilot for further study of the issues.

Any combination of reasons may have contributed to the poor response of the TASH membership including: 1) publication delays caused many members to receive their newsletters after the due date indicated on the survey; 2) some members may be indifferent to the issues; 3) some may oppose this format as a forum for these issues; 4) some may have been "too busy" to fill out the survey; and 5) some members might feel unresolved or unsure about their feelings and therefore felt they could not fill out the survey.

Degree of Exposure. Tables 3, 4 and 5 present the frequency and percent of responses for each rank. A Chi square analysis was done on the rank of "Most" and the rank of "Least" to determine

whether significant differences existed among the sources. Chi square analysis proved significant at the $p < .01$ level for each of the three issues.

Table 3 indicates that most respondents felt that Mass Media provided the most coverage concerning the euthanasia issue. The second largest source indicated was Professional Journals. This rank is consistent with the findings that Euthanasia is covered in the four journals more than the other issues. Schools and Conferences are perceived as offering the least exposure to the euthanasia issue. One reason for this may be that euthanasia was not an issue when many respondents were in school. This also may indicate the reluctance of some professionals to formally talk about the issue. Perhaps discourse about euthanasia is occurring in an informal way with others in the field, as shown in the second column of Table 3.

Insert Tables 3, 4 and 5 about here

Table 4 contains the Degree of Exposure results concerning the selective abortion issue. Data for this issue are very similar to those of the euthanasia issue. Again, Mass Media was perceived as providing the greatest degree of exposure to the selective abortion issue, and Conferences and Schools provided the least. Others in the field was indicated as offering the second most exposure to the issue.

Table 5 indicates that most respondents felt that Professional

Journals provided the most coverage concerning the educability issue. These data are inconsistent with the Journal Review findings of only three educability articles in the four journals in the past 10 years. Several explanations may contribute to this inconsistency: 1) respondents may be referring to other journals (e.g., Analysis and Intervention in Developmental Disabilities, Vol. 1, 1981); 2) journals offer greater coverage when compared with the dearth of coverage in other sources, and 3) respondents may have a broader interpretation of the issue (e.g., any article related to the right to education). Unlike the euthanasia and selective abortion issues, Mass Media was indicated as providing the least amount of coverage of the issue.

Adequacy of Coverage. This section of the survey indicated if the respondents thought that each of the sources should be covering each issue "more," "less," or is doing it in an "adequate" way. Tables 6, 7 and 8 present the frequency and percent of responses in each of these categories for the five sources. A Chi Square analysis was done on each source to determine whether significant differences existed regarding levels of coverage. Chi square analysis proved significant at the $p < .01$ level for all sources on each of the issues. In general, respondents felt that all issues should be covered more or is adequate across all sources; few responses indicated that less coverage should be given to any issue.

Table 6 indicates that most respondents felt that euthanasia should be covered more in Professional Journals, Conferences and in

School, three rather formal modes of dissemination. Others in field and Mass Media showed a fairly even distribution between "more" and "adequate." Very few respondents felt that any of the sources should cover euthanasia "less."

Results for the selective abortion issue (Table 7) again indicate that most respondents want to see more coverage across all sources. Others in field is the only source indicated fairly high on "adequate." Compared to the euthanasia issue, however, more respondents felt that selective abortion should be covered less.

Insert Tables 6, 7 and 8 about here

Table 8 suggests that respondents thought that Professional Journals, Conferences, and Others in field were either in need of more coverage or was adequate in its present coverage of educability. Considering that only three articles on educability were found in the four journals reviewed, it is surprising how many thought it was adequate. Again this might result from a broader definition of the issue or inclusion of other journals. Respondents clearly indicated that Mass Media and School need to cover the educability issue more. Compared to the euthanasia and the abortion issues, very few respondents thought that educability should be given less coverage.

Association Policy. Figure 2 represents respondents' attitudes on the Association either taking a strong position, avoiding a position or presenting a forum for discussion. Members could respond to this section by scoring in one of three ways: 1) take a strong

position or avoid a position, 2) take a strong position or avoid a position, as well as present a forum for discussion, and 3) only present a forum for discussion.

Chi square analysis on taking a strong position versus avoiding a position indicate significance at the .05 level for both euthanasia and educability. Both of these favored the association taking a strong position. A chi square analysis on the selective abortion issue, however, was not significant at the .05 level. The very small difference, however, was in favor of avoiding a position.

On both of the "life/death" issues more respondents indicated that a forum discussion would also be appropriate. Data on the educability issue, however, suggest that most respondents did not want to present a forum for discussion. Considering the large number of responses in favor of taking a strong position, one might speculate that respondents felt that the issue should not even be debated.

Insert Figure 2 about here

Conclusions and Implications

A review of four journals (i.e., JASH, ETMR, MR, AJMD) indicated a relative dearth of articles related to the issues of euthanasia, selective abortion and educability of severely handicapped individuals. A total of only 23 articles were found between 1973 and 1982. A possible relationship exists between the small number of articles and respondents' indication that more journal coverage is needed

across all of the issues. In order to meet this indicated need, at least two alternatives are possible: 1) Journals make a "call for papers" or feature "invited" papers, and 2) professionals should seek the information in other sources (e.g., mass media, science journals).

Although the two "life/death" issues seem to be more controversial than the educability issue (i.e., less agreement among respondents on TASH policy), the data suggest that the least amount of agreement is on the selective abortion issue. There were more "cover less" responses concerning this issue as compared to the other two issues, and there was a fairly equal split between those who indicated that TASH should take a strong position on the issue and those who indicated that TASH should avoid a position on the issue.

In general, most of the data suggest similar perceptions of the euthanasia and selective abortion issues, while responses on educability showed some different trends (e.g., degree of coverage, adequacy of coverage). It is interesting to note, however, that this is not so for TASH policy. Data on this section revealed that euthanasia and educability were similar in that there was a majority of "Take a strong position," and selective abortion had a slightly higher number of "Avoid a position."

It is acknowledged that a 2% return of the survey is certainly of limited validity and that caution should be taken against assuming that these data are necessarily representative of the TASH membership.

However, these data do raise several questions:

1. The role of a journal. Is a journal supposed to reflect the goals and mission of the association? Is it supposed to reflect the majority of membership beliefs? What happens when there is no consensus of beliefs? Who interprets association goals?
2. Advocacy. Who defines advocacy? What issues should come under the realm of advocacy? What are the obligations of an advocacy group?
3. Taking a position. As an organization, what are the implications of assuming a position that is not representative of the entire membership? As an individual, what are the implications of having an organization take a position not representative of your position? What are the implications of an organization, or an individual not taking a stand?

Footnotes

[1] The author achnowledges and wishes to thank Fred P. Orelove for his time and contribution to the design and development of the Survey.

[2] The author wishes to thank the TASH Newsletter for the dissemination of the Survey.

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Davis, J. G. Ethical issues arising from prenatal diagnosis. Mental Retardation, 1981, 19(1), 12-15.

Hardman, M. L., & Drew, C. J. Life management practices with the profoundly retarded: Issues of euthanasia and withholding treatment. Mental Retardation, 1978, 16(6), 390-396.

Hardman, M. L. & Drew, C. J. Parent consent and the practice of withholding treatment from the severely defective newborn. Mental Retardation, 1980, 18(4), 165-169.

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Powell, T. H., Aiken, J. M. & Smylie, M. A. Treatment or involuntary euthanasia for severely handicapped newborns: Issue of philosophy and public policy. Journal of the Association for the Severely Handicapped, 1982, 6(4), 3-10.

Smith, J. D. Down's Syndrome, amniocentesis, and abortion: Prevention or elimination. Mental Retardation, 1981, 19(1), 8-11.

Stevens, H. A. & Conn, R. A. Right to life/involuntary pediatric euthanasia. Mental Retardation, 1976, 14(3), 3-6.

Wolfensberger, W. A call to wake up to the beginning of a new wave of "euthanasia" of severely impaired people. Education and Training of the Mentally Retarded, 1980, 15(3), 171-173.

Table 1

Articles found in JASH, ETMR, MR and AJMD from 1973-1982.

Euthanasia

Affleck, G. G. The right to survive. Mental Retardation, 1977, 15(1), 52.

Affleck, G. G. Physician's attitudes toward discretionary medical treatment of Down's syndrome infants. Mental Retardation, 1980, 18(2), 79-81.

Biklen, D. The Supreme Court and retarded children. Journal of the Association for the Severely Handicapped, 1981, 6(2), 3-5.

Cohen, L. Ethical issues in withholding care from severely handicapped infants. Journal of the Association for Severely Handicapped, 1981, 6(3), 65-67.

Gardner, J. M. Contribution of the German cinema to the nazi euthanasia program. Mental Retardation, 1982, 20(4), 176-178.

Hardman, M. L., & Drew, C. J. Life management practices with the profoundly retarded: Issues of euthanasia and withholding treatment. Mental Retardation, 1978, 16(6), 390-396.

Hardman, M. L. & Drew, C. J. Parent consent and the practice of withholding treatment from the severely defective newborn. Mental Retardation, 1980, 18(4), 165-169.

Powell, T. H., Aiken, J. M. & Smylie, M. A. Treatment or involuntary euthanasia for severely handicapped newborns: Issue of philosophy and public policy. Journal of the Association for Severely Handicapped, 1982, 6(4), 3-10.

Smith, J. D. Down's syndrome, amniocentesis, and abortion: Prevention or elimination. Mental Retardation, 1981, 19(1), 8-11.

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Walmsley, S. A. A life and death issue. Mental Retardation, 1978, 16(6) 387-389.

Wolfensberger, W. A call to wake up to the beginning of a new wave of "euthanasia" of severely impaired people. Education and Training of the Mentally Retarded, 1980, 15(3), 171-173.

Wolfensberger, W. The extermination of handicapped people in WWII Germany. Mental Retardation, 1981, 19(1), 1-7.

Selective Abortion

Abroms, K. I., & Bennett, J. W. Current genetic and demographic findings in Down's syndrome: How are they presented in college textbooks on exceptionality? Mental Retardation, 1980, 18(3), 101-107.

Begab, M. J. The major dilemma of mental retardation: Shall we prevent it? (Some social implications of research in mental retardation). American Journal of Mental Deficiency, 1974, 78(5), 519-529.

Clarke, A. D.B., & Clarke, A. M. Prospects for prevention and amelioration of mental retardation: A guest editorial. American Journal of Mental Deficiency, 1977, 81(6), 523-533.

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Hardman, M. L. & Drew, C. J. Life management practices with the profoundly retarded: Issues of euthanasia and withholding treatment. Mental Retardation, 1978, 16(6), 390-396.

Schneiderman, G., Lowden, J.A., & Rae-Grant, Q. Tay-Sachs and related storage diseases: Family planning. Mental Retardation, 1978, 16(1), 13-18.

Sells, C. J., & Bennett, F. C. Prevention of mental retardation: The role of medicine. American Journal of Mental Deficiency, 1977, 82(2), 117-129.

Smith, J. D. Down's syndrome; amniocentesis and abortion: Prevention or elimination. Mental Retardation, 1981, 19(1), 8-11.

Wolfensberger, W. A call to wake up to the beginning of a new wave of "euthanasia" of severely impaired people. Education and Training of the Mentally Retarded, 1980, 15(3), 171-173.

Educability

Cavalier, A. R. and McCarver, R. B. Wyatt v. Stickney and mentally retarded individuals. Mental Retardation, 1981, 19(5), 209-214.

Levy, W. K., Webster, R. E. & Schenck, S. J. Too retarded to be retarded. Education and Training of Mentally Retarded, 1979, 14(4), 56-59.

Noonan, M. J. Brown, F., Mulligan, M., & Rettig, M. A. Educability of severely handicapped persons: Both sides of the issue. Journal of the Association for the Severely Handicapped, 1982, 7(1), 3-12.

Table 2

NUMBER OF ARTICLES

Journal	Selective Abortion	Euthanasia	Educability	Totals
JASH	0	3	1	4
ETMR	1	1	1	3
MR	5	9	1	15
AJMD	4	0	0	4
TOTALS	10	13	3	26

Table 3

Degree of Exposure

EUTHANASIA

Source	*Most 1 Freq	%	2 Freq	%	3 Freq	%	4 Freq	%	*Least 5 Freq	%
Professional Jrnls	19	22	30	34	16	19	12	15	11	11
Conference	7	8	6	7	19	23	25	31	31	31
School	9	10	3	3	15	18	25	31	35	35
Others in Field	6	7	29	33	25	30	13	16	14	14
Mass Media	47	53	20	23	8	10	6	7	9	9

*Chi ^{2} significant at $p < .01$ for Most and Least.

Table 4

Degree of Exposure

SELECTIVE ABORTION

Source	*Most 1 Freq	%	2 Freq	%	3 Freq	%	4 Freq	%	*Least 5 Freq	%
Professional Jrnls	8	10	22	28	19	23	19	23	17	16
Conference	4	5	6	7	17	21	31	38	27	26
School	9	11	6	7	23	28	11	13	35	34
Others in Field	21	26	27	34	15	19	14	17	9	9
Mass Media	39	48	19	24	7	9	7	9	15	15

*Chi ^{2} significant at $p < .01$ for Most and Least.

Table 5

Degree of Exposure

EDUCABILITY

Source	*Most 1 Freq	%	2 Freq	%	3 Freq	%	4 Freq	%	*Least 5 Freq	%
Professional Jrnls	39	43	29	31	15	17	4	5	2	2
Conference	15	17	25	27	22	25	20	26	5	6
School	15	17	10	11	29	32	21	27	10	12
Others in Field	18	20	22	24	15	17	21	27	12	14
Mass Media	3	3	7	7	8	9	12	15	56	66

*Chi ^{2} significant at $p < .01$ for Most and Least

Table 6

Adequacy of Coverage

EUTHANASIA

Source	More Freq	More %	Less Freq	Less %	Adequate Freq	Adequate %
Professional Jrnls*	61	68	6	7	22	25
Conference*	60	68	8	9	20	23
School*	53	60	10	11	25	29
Others*	39	45	7	8	40	47
Mass Media*	40	46	10	11	37	43

*Chi ^{2} significant at $p < .01$

Table 7

Adequacy of Coverage

SELECTIVE ABORTION

Source	More Freq	More %	Less Freq	Less %	Adequate Freq	Adequate %
Professional Jrnls*	56	63	14	16	19	21
Conference*	59	66	14	15	17	19
School*	50	57	12	14	25	29
Others*	41	47	10	12	36	41
Mass Media*	53	61	11	13	23	26

*Chi ^{2} significant at $p < .01$

Table 8

Adequacy of Coverage

EDUCABILITY

Source	More Freq	%	Less Freq	%	Adequate Freq	%
Professional Jrnls.*	44	51	3	4	39	45
Conference*	45	52	4	5	37	43
School*	58	67	4	5	24	28
Others*	47	55	2	2	37	43
Mass Media*	70	81	4	5	12	14

*Chi ^{2} significant at $p < .01$

Figure Captions

Figure 1. Survey administered to TASH membership.

Figure 2. Number of respondents indicating that TASH should take a Strong Position, Avoid a Position, or Present a Forum for Discussion, on each of the three issues.

TASH MEMBERSHIP SURVEY
ON
TREATMENT AND EDUCATION OF
PROFOUNDLY RETARDED INDIVIDUALS

PART I: BACKGROUND INFORMATION

1. What is your primary role in regard to handicapped persons? (Check one)

__ teacher
__ paraprofessional
__ student
__ school administrator
__ teacher trainer
__ researcher
__ therapist
__ parent
__ other (_____)

2. How long have you been active in the field?

__ 1-3 years
__ 4-6 years
__ 6-10 years
__ more than 10 years

PART II: DEGREE/ADEQUACY OF COVERAGE OF ISSUES

Directions. In the first column in each of the next 3 questions, rank order the degree to which you have been exposed to the issue from the sources listed. Put a "1" next to the source that provided the greatest exposure to the issue, a "2" for the next greatest exposure, and so on through "5".

In the second column, circle for each source listed whether you think it should provide more coverage, less coverage, or is adequate in its coverage of the issue.

Issue 1: Euthanasia (Should treatment be withdrawn or withheld from an individual on the basis of handicap?)

Source of Exposure	Degree of Exposure (Order 1-5)	Adequacy of Coverage (Circle one)		
Professional journals		more	less	adequate
Conferences		more	less	adequate
School		more	less	adequate
Others in field		more	less	adequate
Mass media		more	less	adequate

Issue 2: Educability (Are all children capable of being educated?)

Source of Exposure	Degree of Exposure (Order 1-5)	Adequacy of Coverage (Circle one)		
Professional journals		more	less	adequate
Conferences		more	less	adequate
School		more	less	adequate
Others in field		more	less	adequate
Mass media		more	less	adequate

Issue 3: Selective Abortion (Should prenatal diagnosis be used as a decision-making tool for selective abortion of severely impaired fetuses?)

Source of Exposure	Degree of Exposure (Order 1-5)	Adequacy of Coverage (Circle one)		
Professional journals		more	less	adequate
Conferences		more	less	adequate
School		more	less	adequate
Others in field		more	less	adequate
Mass media		more	less	adequate

PART III: ASSOCIATION POLICY

What role do you feel that TASH should assume concerning each of these issues? (For each issue check all that apply.)

Issues	Should take a strong position	Should avoid taking a position	Should present a forum for further discussion
Euthanasia			
Educability			
Selective Abortion			

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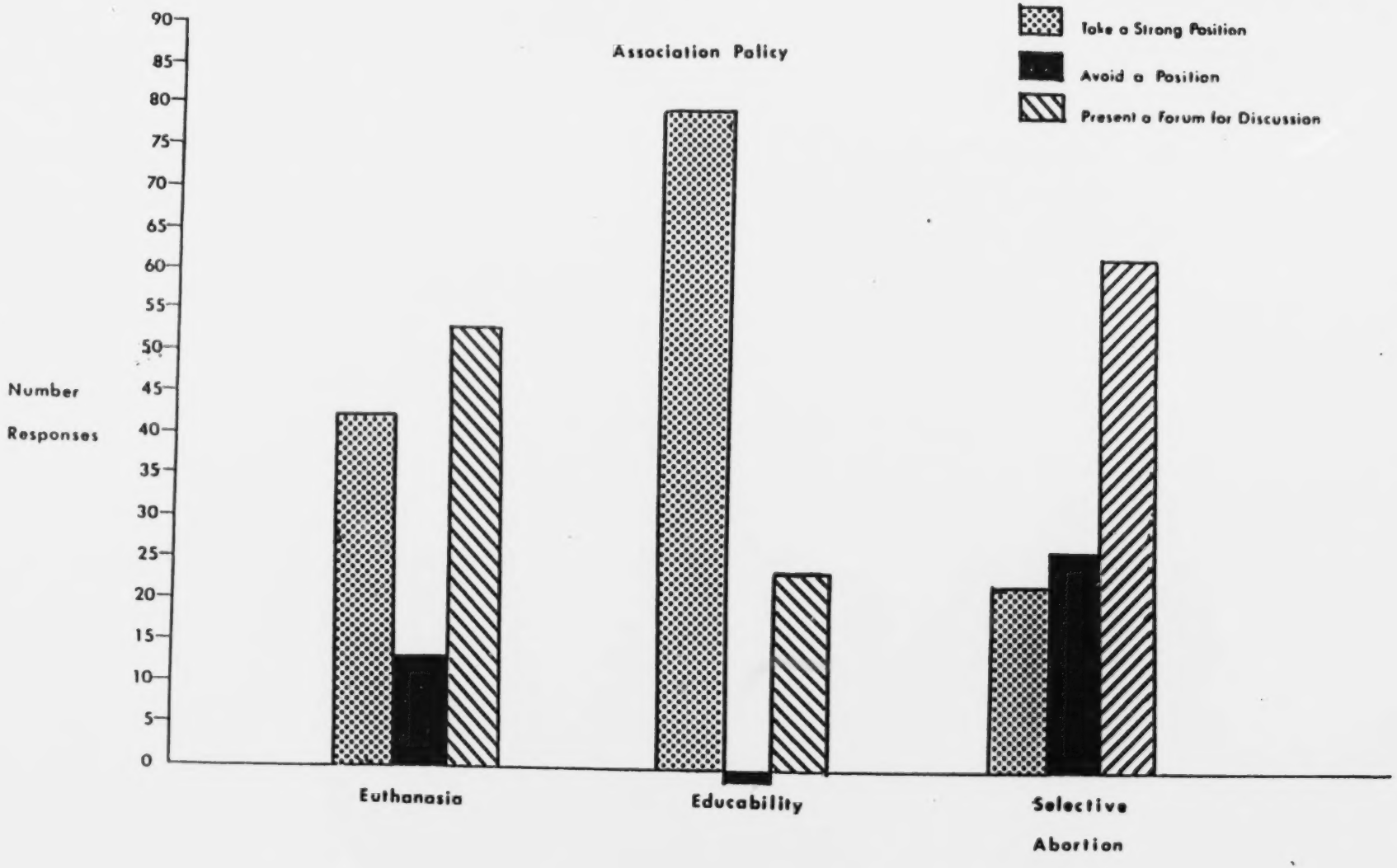
Association Policy
Take a Strong Position
Avoid a Position
Present a Forum for Discussion
Number Responses
90
85
80
75
70
65
60
55
50
45
40
35
30
25
20
15
10
5
0
Euthanasia
Educability
Selective Abortion